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ABSTRACT

This monograph presents the philosophy of the Rehabilitation Research and Training Center on Supported Employment (Virginia) concerning consumer advocacy and supported employment for persons with disabilities. An introductory chapter looks at origins of supported employment, its relationship to consumer advocacy, and challenges facing these fields. Eleven issues are then addressed, including: (1) career advancement; (2) choice and empowerment; (3) systems barriers; (4) families; (5) consumer and professional partnerships; (6) recognition of qualifications separate from education; (7) affordable and accessible housing; (8) access to assistive technology; (9) consumer feedback to professionals; (10) supported employment group options; and (11) referral and/or resource systems. Another chapter looks at implications of a consumer empowerment approach to the design of human service systems. A final chapter uses a case study format to describe the organization and development of a consumer advocacy organization, including selecting a leader, developing a communication system, establishing a funding base, and identifying funding options. (DB)

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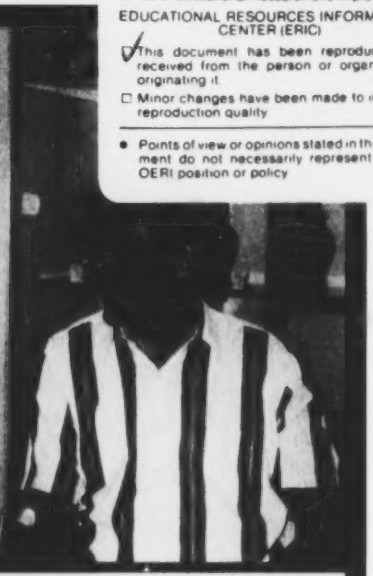

Consumer Advocacy and Supported Employment: A Vision for the Future

EC 301 554

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Consumer Advocacy and Supported Employment: A Vision for the Future

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Consumer Advocacy and Supported Employment

"... Supported employment was developed to give individuals with disabilities a choice in the labor force. This service model focuses on consumer interest and provides an opportunity for individuals to identify a job, specify the working conditions, determine the wage level, select the job location, and decide the hours that they will work."

by: Paul Wehman

Consumer Advocacy and Supported Employment

"The roots of supported employment are deeply entwined in consumer interests, choice, and inclusion. These roots are what has made supported employment one of the most popular and sustainable programs in the United States"

In recent years there has been a rekindling of interests in expanding services and improving accessibility for people with physical disabilities and sensory impairments. Consistent with the movement in society toward automation and application of technology, there has been a new law signed by President Bush called the Americans with Disabilities Act (ADA). This law and the accompanying regulations, which were published in July 26, 1991 in the Federal Register, provide the impetus for people with all disabilities to participate in the labor force, as well as, the community to a greater extent.

The resulting attention to assisting people with physical disabilities, in addition to continued interest for those with mental disabilities, has increased the focus on individuals with disabilities speaking for themselves. Specifically, there are hundreds of thousands of people with a variety of disabilities who are speaking for themselves. They are voicing their concerns and needs; and,

yes, even angers and frustrations at a society which has forgotten them. While it is always difficult to trace the beginning of new directions in service priorities, it would appear that a major impetus for greater consumerism, technology, and family involvement comes directly from legislation like the American With Disabilities Act. When new directions are carved out with impending legislation, the general reason is an existing vacuum in the law and accompanying practices.

For example, millions of people with disabilities cannot get into movie theaters, grocery stores, shopping malls, and cannot access restaurant facilities in public places. Thousands of highly capable individuals who could work are either passively or actively discriminated against by business and industry because of an unwillingness to make often very inexpensive accommodations. The thrust of consumerism on the part of many people with physical disabilities and sensory impairments is to function independently and not depend on a paternalistic professional service delivery system which has historically ignored them.

With the advent of consumer rights, greater emphasis on client involvement in planning and decision making, and the passage of the Americans with Disabilities Act; many professionals, consumers, and families are wondering what this means for supported employment. Are the Americans with Disabilities Act and supported employment compatible? Do consumer advocates and Centers for Independent Living have common issues with supported employment programs? In short, how does the welcomed trend toward consumer involvement relate to supported employment? We at Virginia Commonwealth University Rehabilitation Research and Training Center have asked ourselves these very

questions and find the two directions highly consistent and parallel with the mutual goal of inclusiveness and integration into the community. Our conclusions and philosophies on consumer advocacy and supported employment are contained in this relatively short monograph.

Supported Employment: A Look At It's Roots

It may be beneficial to go back into time and take a look at how supported employment began. That is, take a look at how and why supported employment emerged as an attractive alternative for people with disabilities. As we have said on numerous occasions, new concepts do not arise unless there is a need for them. Supported employment emerged because there were thousands upon thousands of people with severe mental disabilities who were viewed as being incapable of working by most service providers and, for that matter, advocates. Their options in life were to be in a day programs, adult activity centers, sheltered workshops, or to stay at home, or, perhaps even live in institutions. In the mid to late 1970's, a number of professionals began to experiment with different ways of providing services. The reason for this experimentation was primarily to meet a need. The need was for people to obtain competitive employment, earn a decent wage, to develop a real work history, and to realize community inclusiveness.

Supported employment was developed to give individuals with disabilities a choice in the labor force. This service model focuses on consumer interest and provides an opportunity for individuals to identify a job, specify the working conditions, determine the wage level, select the job location, and decide the hours that they will work. With 72,000 people

currently working in supported employment (Wehman, 1991), it is clear that more and more individuals with severe disabilities are asserting their rights and going to work for the first time.

Supported employment will not succeed without consumer involvement. Supported employment programs cannot be effective and will not flourish without consumer and family participation, support, involvement, and a willingness to take the necessary risks that are inherent, with any competitive employment. The early consumers that entered the work force in the late 1970's and early 1980's were pioneers. They were willing to take the risks of losing their safe spot in an adult day program and enter competitive employment. In most states there were limited support systems to help replace them if they failed.

We think that the parallels between this type of risk taking and pioneering spirit by people with severe mental disabilities dramatically parallels visionary thinking and activities on the part of people like Justin Dart in the formulation of the American's With Disabilities Act. The roots of supported employment are deeply entwined in consumer interests, choice, and inclusion. These roots are what has made supported employment one of the most popular and sustainable programs in the United States even in the face of one of the more severe recessions that this country has seen since World War II.

What Are the Parallels Between Consumer Advocacy and Supported Employment?

We see numerous overlaps in philosophies and a significant number of parallels between the recent emphasis on consumerism and the supported employment programs which

have rapidly emerged across the country. What follows are a series of these parallels and consistencies. All people who are working in the field of disability, but especially those who are service providers, should be aware of these philosophies and parallels to include the following:

1. **The focal point of consumer advocacy and supported employment is persons with disabilities.**
2. **Real work is the outcome which consumer advocacy and supported employment programs both wish to see happen.**
3. **Consumers participating in consumer advocacy and/or supported employment programs have had their potential grossly underutilized.**
4. **Supported employment and consumer advocacy programs have proven themselves to be sustainable.**

1. **The focal point of consumer advocacy and supported employment is persons with disabilities.**

Traditionally programs that provide services to people with disabilities have delivered them in large groups and in an aggregate format, i.e., sheltered workshops, and large institutional settings. Supported employment does just the opposite. Highly effective supported employment programs, for the most part, provide individualized services and

support to the individual worker based on what he or she wants and needs. For example, if the consumer in question has a brain injury and does not want or need frequent visits to the work site from an employment specialist, then the employment specialist will do everything in his or her power to respect that wish. On the other hand, if a person with a long-term mental illness is extremely nervous and anxious about employment, as is a family member, then the employment specialist will make himself or herself available on a more frequent basis.

2. **Real work is the outcome which consumer advocacy and supported employment programs both wish to see happen.**

In so many programs that serve individuals with disabilities, the outcomes and goals are very unclear. The bureaucracy of service delivery seems to suffocate the whole intent of the program, and the individual with a disability is classically lost "in the shuffle." A major strength of both the consumer advocacy movement and the supported employment movement is that the goals and outcomes are very clear in terms of what all wish to see happen. A competitive job with the opportunity to earn a decent wage and work in good conditions is paramount. This type of singular focus becomes very empowering to the professionals, advocates, and consumers who work in this environment. All involved know what they are there for, and how their success or lack of progress will be measured.

3. **Consumers participating in consumer advocacy and/or supported employment programs have had their potential grossly underutilized.**

Whether it is people with severe mental retardation, severe autism, and/or other severe mental disabilities in the 1980's or people with severe spinal cord injuries or severe cerebral palsy in the early 1990's; all of these individuals have been "wasted" in terms of their human

potential. These people have been considered by professionals as well as the business and industry community to have little to offer, to be too expensive to work with, and generally to be poor investments for vocational rehabilitation. What could be more devastating to one's self esteem than to be written off in this fashion? Yet, in fact that is exactly what has happened, resulting in perhaps the most striking parallel between the two movements. The same motivations for those that wrote the Americans with Disabilities Act were shared by those that pushed and promoted supported employment opportunities for thousands of people with mental disabilities.

4. **Supported employment and consumer advocacy programs have proven themselves to be sustainable.**

A fourth parallel which immediately comes to mind is the fact that weak programs, weak concepts, and "flash-in-the-pan" innovations will not last. Agency heads will not fund such programs, and they will not generate the type of outcome data that warrants funding in tight times. Supported employment began approximately twelve years ago and has endured during two recessions; one in 1981-82 and one in 1990-91. Supported employment has stood the test of 37 out of 50 states running deficits within the last year, and it has withstood the still all too frequent detractors who are only satisfied with the status quo of human service delivery programs. Consumer advocacy programs and other advocates of the Americans With Disabilities Act have fought for over five years, and in some cases even longer, to get the type of federal legislation in place which can begin to right the wrongs which have developed into our society's attitudes towards people with disabilities.

Consumer advocacy has staying power, because, like supported employment, it is the right thing to do. The best concepts are not only those that work, but those that make sense to people on a moral as well as common sense basis. After all, why wouldn't one seek input from the very people that are being served in disability programs? Why wouldn't those individuals help run those programs and take leadership roles in them? Why wouldn't those individuals with disabilities provide feedback about how to change those programs? It is common sense to do this; it is the right thing to do; and it is only a matter of time before this type of consumer advocacy and involvement spreads like wild fire.

Consumer Advocacy and Supported Employment: What Are the Challenges?

There are a number of issues which must be resolved and taken into account as we consider the linkage of consumer advocacy and supported employment concepts. The first issue is that each of these major concepts have different constituencies of people with disabilities. For example, the consumer advocacy movement in recent years is most closely identified to people with physical disabilities and other groups of people with disabilities that are able to articulate for themselves. They are able to express what their needs, wishes, and hopes are in terms of society being responsive to them.

On the other hand, supported employment has been and continues to be most closely aligned with people who have mental retardation and mental illness as their disability. These are two groups of people who are often unable to clearly articulate for themselves or receive the respect that is necessary to make their wishes and needs known. Subsequently, the idea

of an employment specialist or a job coach arose to assist this group of individuals in gaining entry into the labor force. In fact, in the late 1970's when we began our work in supported employment, the term used to identify the supported employment service provider was "trainer-advocate." This term was used to recognize the dual role of the employment specialist on behalf of the person. Hence, the first issue that must be resolved in merging these concepts is for the two major groups of disabilities, physical and mental, to communicate more frequently and understand the differing points of view that each hold in wanting to make change in the system that provides services for people with disabilities.

A second very powerful issue involved is that those who are identified most closely with consumer advocacy generally have a number of goals that they wish to achieve in systems change. That is, transportation, personal care attendants, and improvements in quality of residential choices become paramount and overriding factors for thousands of people who are promoting greater consumer advocacy. Specifically, this means that as important as a positive vocational outcome is, there other factors which weigh equally if not more important.

Those persons who are identified as primarily supporters of integrated and supported employment programs tend to have a somewhat more limited agenda. They are pushing work as the main change that they want to see occur in the system. In this sense, both groups have much to offer each other, since there are many people with physical disabilities who could greatly benefit from supported employment. In similar fashion, many supported employment participants and staff need to be more vocal in taking an activist role in other important life areas, i.e., transportation, independence in community living and so forth.

A third issue which needs to be resolved between the two groups is a very simple one but one that has a great deal of depth. Specifically, we are raising the point that consumer advocacy proponents do not always understand the philosophies or practices that are associated with supported employment. At the same time those individuals who are narrowly focused on supported employment as the only type of service issue do not recognize many of the consumer satisfaction, independence, and nonwork disability incentive issues which occur on a daily basis for people who are associated with consumer advocacy programs. It is essential that both groups begin to attend each other's conferences. There needs to be greater professional communication and dialogue and a far greater integration and merging of mutual goals. The fire power of both groups working together as a cohesive lobbying force can have a tremendous impact on changing attitudes, values, and practices in society as well as influencing state and federal legislative action.

What Does the Future Hold?

We see a very exciting vision of the future which merges the best of consumer advocacy and involvement with the most sophisticated job matching technologies and business and industry commitments. We see a period of time when assistive technology, electronics, robotics, and technological devices which have not even been invented yet will come into the work place to help empower the worker with a disability, his coworker or supervisor, and, as needed, employment specialist. In a sense, the employment specialist, other agents of supported employment programs, or Centers for Independent Living will provide the impetus for these technologies to be implemented.

The future of consumer advocacy programs, supported employment programs, Centers for Independent Living, technology transfer, and human behavioral interventions is in our hands. We have the greatest opportunities that we have ever had to integrate people with disabilities into the labor force. As the U. S. economy comes out of this recession, there will be jobs in all sectors, part-time and full-time for people with disabilities. The service delivery system and the community must work together to make this a reality.

Supported Employment Service Issues

"As advocates we are committed to change. We need to recognize that change takes time and that advocacy is a process."

by: Chuck Chumbley
Mike Collins
JoAnn Elliott
Linda Geake
Mary Grant
James Hague
Thomas Hock
Jackie Moore
Tasha Toth

Supported Employment Service Issues

"It is the hope of all group members that persons with disabilities are afforded the same equal opportunities as someone else with the same qualifications"

My dream job would be working in sports; owning my own business; making money doing something I'm already involved with and enjoy; being my own boss; having a career with room for advancement; choosing my own employment situation. These were the opening remarks made by a group of self described supported employment consumer activists when asked **"What is your dream job?"**

The mission of the VCU-RRTC is to provide research, training, and leadership related to supported employment of citizens with developmental and other severe disabilities. Guided by this mission, we felt that it was important for service providers, policy makers, rehabilitation professionals, researchers, personnel trainers, and family members to hear from the constituents of supported employment services. With 75,619 persons currently participating in supported employment across the country, there is little argument that this model has increased the choices available to individuals with severe disabilities who were previously excluded from the competitive labor force.

Distinguished by the individualized job placement assistance, the intensive on-the-job support and training, and the personalized follow along services, supported employment services has spelled success for tens of thousands of persons with severe disabilities. Yet, despite these impressive outcome data and the critical role of consumer choice and empowerment in supported employment, we felt that it was necessary to investigate whether individuals are choosing their own jobs and ultimately controlling their own careers. Nine self-advocates volunteered to assist the Virginia Commonwealth University Rehabilitation Research and Training Center on Supported Employment (VCU-RRTC) to identify issues facing consumers of supported employment services.

In a day long meeting, these supported employment self-advocates discussed their experiences with supported employment services by identifying what was working and what needed to be changed. The purpose of this Consumer Focus Group was to participate in a problem-solving session centered around supported employment implementation and/or service issues. First, a problem was defined as a situation that group members wished to change. The group then "brainstormed" solutions and generated discussion of the topic. The meeting was made up of individuals participating in one of three different and distinct roles: group member role, facilitator role, or recorder role.

All **group members** had first hand experience with supported employment services and were encouraged to participate actively throughout the entire day. Members were instructed to keep the facilitator and the recorders in their impartial roles. Although the facilitator made procedural suggestions, the group members generally determined the course of the Consumer Focus Group. The role of the **facilitator** was to serve as a nonpartisan

"servant" to the group. This individual was not permitted to evaluate or contribute any of her own ideas, issues, or concerns. Her responsibilities were to perform the following tasks.

ROLE OF THE MEETING FACILITATOR

- **Keep group energy focused**
- **Keep group members on task**
- **Suggest methods or procedures for conducting the meeting**
- **Protect all group members from attack**
- **Provide opportunities for all group members to participate**

Doyle & Straus, 1976

The third role that defines the participants of the Consumer Focus Group was that of **recorder.** Two individuals served as recorders for group members. They remained neutral throughout the meeting and did not evaluate any ideas that were presented by group members. Each recorder documented information and ideas as they were presented. This continuous recording method, sometimes referred to as a group memory, produced a useful tool that the Focus Group referred to and referenced throughout the day. Specifically, participants used the group memory to collapse similar ideas and issues and to provide further clarification on specific topics. The following table highlights the role of the meeting recorder who assisted the Consumer Focus Group.

The Role of the Meeting Recorder

- **Remain neutral throughout the meeting.**
- **Write down basic ideas as presented by an individual group member.**
- **Use the words of the individual addressing the group.**
- **Record ideas on large sheets of paper in front of members.**
- **Display group memory on the walls around the meeting room.**

Doyle & Straus, 1976

The Consumer Focus Group began their work by discussing what was preventing group members from obtaining their "dream job." From this discussion a list of **79 issues** were generated. These issues were the personal experiences of group members in seeking and/or obtaining community integrated competitive employment. Group members then used the group memory to collapse the identified issues into **eleven distinct categories.** Members felt that it was important to end the process on an upbeat note with a vision for **all** to work towards. After brainstorming several ideas for a closing activity, group members decided to generate a list of "dream employment supports" that could assist all persons, regardless of their disability, in obtaining their dream job.

SUPPORTED EMPLOYMENT SERVICE ISSUES

1. **Career Development**
2. **Choice**
3. **Systems Barrier**
4. **Families**
5. **Consumer and Professional Partnerships**
6. **Qualifications not Education**
7. **Affordable and Accessible Housing**
8. **Access to Assistive Technology**
9. **Consumer Feedback to Professionals**
10. **Supported Employment Group Options**
11. **Referral and/or Resource System**

The following section of this monograph presents the supported employment issues and concerns as described by the Consumer Focus Group. All self-advocates agreed that the list of issues presented in this portion of the monograph are comprehensive and represents group members experiences while seeking community integrated employment situations. Each participant was provided an opportunity to comment on all of the eleven issues in an

effort to fully define the scope of a particular issue, the barriers, and in some cases the available resources. The content has been arranged in a particular fashion to help recapture the energy and excitement that group members expressed with regard to those issues that continue to affect their everyday life. It is the hope of all group members that persons with disabilities will be afforded the same employment opportunities as anyone else with the same qualifications.

ISSUE 1: Career Advancement

"I've had three different jobs, and I didn't like any of them.. Now I'm a utility worker/ dishmachine operator, but I'm tired of that... I have no place to go to get a job with room for advancement."

James Hague

Career development is an important consideration for any adult looking for employment. Historically, we have been viewed in terms of our disability rather then our qualifications. This type of perspective has lead rehabilitation professionals and employers to: 1) view persons with significant disabilities as unemployable; or 2) direct individuals with disabilities into a limited number of seemingly dead end occupations. When we attempt to fight against this type of stereotyping by suggesting an unusual or a challenging career, agencies/service providers have often refused to support us in our career decisions. We get labeled as "unrealistic" and are told that we have not dealt with our disability. Typically, we end up getting referred to career counseling so someone can help us become employable. Consumers and rehabilitation professionals must develop a common understanding and sensitivity to each others goals. Once we have accomplished this, we can focus on employers' attitudes and develop creative strategies that will move beyond the personnel departments and into the offices of managers and supervisors, who actually make the hiring decisions.

ISSUE 2: Choice & Empowerment

"Nobody asked me what kind of job I wanted...I would like a different job in the future...My counselor told me to finish the job that I have before I move to another."

Tasha Toth

Choice and **empowerment** are the new words of the 1990's. All too often the system makes decisions about our lives without involving us in the process. When we are afforded the opportunity to get involved in the process, there are few options. Generally, our decisions are to either choose the service, as the providers developed, or choose no service at all.

Real choice and empowerment will exist when we have an opportunity to assist in shaping service options and the delivery practices of the services that we use. Professionals must be willing to share all their information in regard to the strength and weakness associated with the service options that they deliver. We want to be able to choose where to work, where to live, the type of employment support that we need, and from whom we would like to receive support services. We acknowledge that this will not occur until consumers begin to speak out and service providers develop the sensitivity to bring persons with disabilities into the planning and decision making arenas.

ISSUE 3: Systems Barrier

"I waited for two years on a caseload only to find out that VR would not pay my school program to find me a job, because my parents make too much money. I think that I really fell through the cracks."

Thomas Hock

Many service systems today are attempting to answer **all** the needs of persons with disabilities. This is an impossible situation and sets the service provider, as well as the consumer, up for failure. We must begin to recognize the talent in ourselves and start to work the system rather than looking for someone to blame. Part of working the system is obtaining information and ensuring that we know how the system operates. Getting this information can, at times, be very difficult. We should not feel ashamed to ask questions and to demand, if necessary, that the information be explained until we fully understand.

There is no question that change is occurring in rehabilitation services. Who would ever have thought that there would be someone like a job coach to assist at our job site! Yet, systems are slow to change. We must not allow ourselves to sit idly on caseloads for years at a time waiting for someone to call our number. Rather, we should appeal professional decisions as we work to build community supports that will assist us in becoming real members of our own community.

ISSUE 4: Families

"My family has assumed the role of protector, and I'm not viewed as an independent individual."

Chuck Chumbley

It seems that those people who care the most for us have become one of the most difficult hurdles for people with disabilities to confront. The role of a parent is centered around protecting their child from the different forms of pain in our society. Many parents have trouble seeing their grown children as adults, capable of making independent decisions. Yet, parents of children without disabilities have an opportunity to watch their child successfully take risks gradually over time. This has not been the experience of parents who have children with disabilities. Generally, we have grown up with segregated and highly supervised experiences, rarely making choices or taking risks.

Our decisions to take on new experiences are greatly influenced by our parents and our well meaning family members. We want to make our own decisions, hear positive messages about our abilities, and be encouraged to try new experiences. We realize that we will not be successful at everything that we try, but families need to let go and support us as we take risks. Taking on the system is hard enough without having to struggle with the people you love.

ISSUE 5: Consumer and Professional Partnerships

"Professionals listen but they don't hear...They want to fit you into some stereotype that they learned in school."

Mary Grant

Often, professional service providers think they know what is best for the people that they serve. This general air of condescension towards us has many negative and far reaching implications which effect our ability to obtain employment. When professionals view persons with disabilities as "helpless," employers, family members, and the general public accepts this same attitude. The end result is the continuation of negative attitudes and stereotypic images of persons with disabilities throughout the general public.

Professionals providing vocational services to persons with disabilities are engaged in a needed service. However, this will not be a quality service until professionals and consumers enter into an equal partnership with a common bond of trust and respect that guide interactions. Professional and consumers must be willing to discuss their different roles and be open to sharing power and control. Once this partnership is formed, we will see more consumers taking on leadership roles in shaping the policies and practices of the services that profoundly impact their lives.

ISSUE 6: Qualifications not Education

"We need to look at education as separate from the qualifications necessary to do a job."

Mike Collins

"You are over educated for this position." "You do not have the right educational background for this position." Anyone looking for a job has heard one or both of these statements. Yet, when we hear employers make these statements, the conversation is not exclusively about educational requirements. More often than not, we are confronting a form of prejudice. Many individuals who are considered intelligent by society's standards view us as having limited aptitude. Quality job placement decisions can only be made when consideration is given to the relationship between the specific duties of the position and the individual qualifications of the job candidate. This method will: 1) reduce personal assumptions or prejudice from guiding the employment decision making process; 2) encourage employers to develop valid job descriptions; and 3) provide a natural opportunity to discuss reasonable accommodations to maximize job performance. With the advent of ADA, perhaps individuals with disabilities and professionals will work together to ensure that these changes actually occur in the labor force.

ISSUE 7: Affordable and Accessible Housing

"I need affordable housing in my community...Even when you can find a place to live it isn't accessible."

Chuck Chumbley

Presently, persons with disabilities face a critical shortage of affordable and accessible housing options. This lack of housing has been, and continues to be, a major policy issue facing all persons with disabilities. We will never be totally accepted by the general public until we are afforded the opportunity to live in our own communities and form relationships with our neighbors. As members of a community, we will be able to develop friendships and become part of the diverse social fabric that exists in our communities.

Some localities have developed residential service programs for persons with disabilities. However, a closer look at these programs reveals that there are huge waiting lists with extremely limited housing opportunities. Typically, these programs exclude persons who need personal assistance services or adaptive equipment devices, because support services of this nature are generally nonexistent in most communities. Local Centers for Independent Living can be a major source of support as individuals canvas their locality for accessible housing. Yet, unless a comprehensive system of residential alternatives is developed, we will continue to be spectators in our own communities.

ISSUE 8: Access to Assistive Technology

"Having some kind of revolving loan program for assistive technology devices would sure help me."

Mary Grant

New technological advancements are being made everyday in our country. Yet, people with physical disabilities are still having difficulty accessing information and services that will assist them in acquiring the necessary assistive technology devices to achieve particular goals in their lives. Federal, state, and local experts need to come together and analyze the gaps between information, services, and funding.

The availability of assistive technology continues to be an important issue for persons with disabilities. There are very few outreach programs aimed at making persons who could benefit from assistive technology aware of what is currently available. Persons with disabilities are clamoring for information on where and how to obtain services. Cost is a particularly important issue concerning assistive technology. While not all technology related assistance is expensive, some of it can be cost prohibited. Community funding options, all too often, leave consumers and professionals unsure of how to obtain support. We need to work with service providers and develop creative solutions, such as revolving loan programs, to ensure that assistive technology reaches all persons in need.

ISSUE 9: Consumer Feedback to Professionals

"I get evaluated all the time, but there is no opportunity for me to tell the same people what is working and what is not working for me."

Linda Geake

Individuals with rehabilitation and business backgrounds have organized agencies across the country aimed at serving persons with disabilities. Yet, we are generally not part of the management teams in these organizations. With support of recent civil rights legislation and the Americans with Disabilities Act (ADA), people with disabilities are beginning to demand that their voices be heard.

Persons with disabilities should be part of the planning and the evaluation components of service programs. In order for this to occur, we must begin to serve in key agency positions and participate in agencies' formal evaluations and monitoring processes to track the quality of services. When these two very significant changes occur, we will begin to see people with disabilities evaluating the professionals that serve them. Ultimately, this will elevate us from our present roles as second class citizens. There will be fewer fund raising events devaluing persons with disabilities by using "pity" as a central theme. Agencies will know that they are providing quality services that people with disabilities recognize and value.

ISSUE 10: Supported Employment Group Options

"I didn't know may salary was going to be below minimum wage... Now I'm locked into an enclave and having difficulty moving out."

Tasha Toth

Supported employment is competitive work that occurs in integrated settings for persons with severe disabilities. Presently, there exist two major models of supported employment: 1) the individual placement option and; 2) the group option (i.e., enclave or mobile work crew). Regardless of the supported employment model that is being used, outcomes are directly affected by the amount of consumer involvement in identifying career choices and directing the entire supported employment process.

Professionals must stop making easy business deals when developing a supported employment group option. All too often these "deals" leave us on sheltered workshop payrolls, working in back rooms where we can't see our co-workers, or receiving half the wages of other company employees. Consumers of supported employment services need to speak out when we are dissatisfied. If we stop taking unacceptable situations, service providers will be forced to develop adequate employment options. We want to be afforded the same dignity and financial outcomes that service providers find on their jobs!

ISSUE 11: Referral and/or Resource System

"We need to have one place to go for information...It would help us to know what services are out there and how to get them ."

JoAnn Elliot

In the last several years, there seems to have been an explosion of new information since the reauthorization of the Vocational Rehabilitation Act, the passage of the Technology-Related Assistance for Individuals, and the new Americans with Disabilities Act. Communities are responding to this legislation by creating and expanding services for persons with disabilities. Therefore, it is almost impossible to stay informed of what services are being offered in any one community.

Typically, professionals with one agency have very little information concerning the services of another agency. Supported employment personnel don't know about Social Security. Social Security representatives don't know about Vocational Rehabilitation Services. Vocational Rehabilitation Services counselors don't know about Medicaid.

These problems could be alleviated if communities had some central Information and Referral System (I&R). This accessible system would connect us to the appropriate service and/or support in our communities. A system such as this would be up-dated on a continuous basis to keep all information current. An I&R system could be a valuable resource to anyone who has difficulty accessing his or her community, as well as to professionals.

Summary

At the close of the day, the Consumer Focus Group spent time highlighting some of the major discussion points of the day. These discussions helped group members to clearly define the differences between high and low quality supported employment programs. This resulted in a lively discussion by the self-advocates as they constructed a vision statement.

It has been the experience of group members that the quality of supported employment services varies from provider to provider. In poor quality programs, the job coach (also known as an employment specialist) and the vocational rehabilitation counselor do not work well together. These low quality supported employment programs do not: 1) present consumers with multiple career options; 2) obtain access to assistive devices to increase independence or; 3) develop strategies to assist in performing our jobs more efficiently.

In contrast, high quality supported employment service providers realize that individuals with disabilities are searching for the same general qualities in an employment situation, as (so called) nondisabled individuals look for when attempting to find a new job. Quality supported employment services recognize that we, like nondisabled persons, may need to take several jobs before we settle on a particular company and a career. When an employment situation doesn't work out, the job coaches in these programs don't tell consumers that they have messed up. Instead, everyone sits down together to determine what has been learned from the work experience, and how this information should be used to secure a new job.

Consumer activists, like Ralph Nader, would encourage all Americans to become better consumers. Persons with disabilities need to join the consumer movement and critically evaluate the services that they receive. Part of being a good consumer will require persons

with disabilities to learn their rights, ask tough questions, speak up when they disagree, and appeal professional decisions when necessary. If every community had the following **dream employment supports**, quality services would be a natural outcome. Group members envision a future community that incorporates the entire list of employment supports, and persons with disabilities are living, working, and recreating along side other community members. This futurist vision can be achieved if everyone begins working today in all communities across the country.

DREAM EMPLOYMENT SUPPORTS

- **Transportation everywhere**
- **Accessible housing**
- **Committed Job Coaches**
- **Hard working Rehabilitation Counselors**
- **Career advancement**
- **Access to the training that you want**
- **Employers who do not see your disability**
- **People who don't discriminate**
- **People with disabilities acting in political limelight**
- **Consumer feedback to professionals**
- **Choice**
- **Information and Referral System**
- **Equal opportunity**

A Consumer Empowerment Approach to the Design of Human Service Systems: Implications for Supported Employment

"Consumer empowerment is beginning to be viewed as the driving force behind the development, implementation, and evaluation of human services."

by: John Kregel

A Consumer Empowerment Approach to the Design of Human Service Systems: Implications for Supported Employment

"Too frequently, the task of meeting the needs of individuals with disabilities results in human service professionals attempting to impose their own values on individuals with disabilities"

The traditional relationship between human service professionals and consumers might best be described as the "we know best syndrome." In the previous chapter, members of a self-advocacy focus group stated that, in their experience, some professionals viewed persons with disabilities as "helpless" and actually contributed to the negative stereotyping of persons with disabilities among the general public. These same professionals, when engaged in the task of meeting the needs of individuals with disabilities, all to often attempt to impose their own values on individuals with disabilities and thereby usurping their rights to make the major decisions affecting their lives. In the name of "normalization", human service professionals sometimes develop a paternalistic attitude toward individuals with disabilities, resulting in a "superior-inferior" relationship between providers and customers. Fortunately, consumer empowerment has emerged as the major

philosophical basis of programs for individuals with disabilities in the 1990's. Consumer empowerment provides an opportunity for individuals with disabilities to direct their own lives and control the services they receive.

This chapter describes the potential effect of consumer empowerment on supported employment programs. First, the consumer empowerment concept is discussed and compared to traditional approaches of human service delivery. Second, the characteristics of a supported employment program which emphasizes consumer empowerment are illustrated. Third, specific recommendations are offered which would greatly increase the rate at which individuals with disabilities in supported employment programs are able to make choices and exert control over their careers.

The Emergence of Consumer Empowerment

For the past twenty years, the concept of ***normalization*** has been the philosophical and ideological cornerstone of human service programs for persons with developmental and other severe disabilities. Beginning with Nirje's (1969) conceptualization of the normalization principle as making available to individuals with disabilities "patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society" (p. 181), normalization represented a major philosophical shift away from segregated services for people with disabilities. Wolfensberger (1972) expanded the concept to not only include the outcomes or goals of human service programs, but also the means (strategies, techniques, technologies, etc.) used to achieve these goals. Wolfensberger (1977) later refined the term further to remove the notion that individuals with disabilities should somehow be

"shaped" through appearance and experiences to fit the statistical norm for their community. Rather, normalization focuses on enabling individuals to lead lives that are **valued** by other members of their community.

During the 1970's and 1980's, normalization became quickly accepted as the guiding philosophy of the majority of human service programs. The administrators of sheltered workshops, community residential programs, even large state institutions adopted mission statements for their agencies which featured strong commitments to normalization as the primary purpose for their services. Major components of the concept were imbedded into numerous federal laws.

Normalization has had a tremendous positive impact on the lives of millions of individuals. It did much to eliminate the overcrowding, lack of individualization and purposeful activities, and isolation from other people and ordinary places that plagued earlier human service programs. Normalization should be viewed as directly responsible for, or significantly contributing to, the increase in community residential alternatives, the development of community-based employment programs, the rise in the self-advocacy movement, and the trend toward inclusive, integrated educational opportunities.

The 1990's will see the end of normalization as the philosophical basis underlying human services. In its place, ***consumer empowerment*** is beginning to be viewed as the driving force behind the development, implementation, and evaluation of human service programs. This is not meant to imply that the importance placed on the concept of normalization was misplaced, or to detract from the immense positive effect the adoption of the normalization philosophy had on the lives of individuals with disabilities. However, at

least three key factors have combined to lead to the emergence of consumer empowerment as the focal point of human services programs in the 1990's.

1. **Recent changes in public policies affecting individuals with disabilities are based on the assumption that discrimination is the greatest obstacle confronting persons with disabilities as they attempt to live independent and productive lives.**

Many individuals have expressed the view that the accepting, supporting community - described in normalization literature as providing a mutually supportive network of relationships exists in far too few areas of our country. On the contrary, many individuals with disabilities are quick to cite instances of discrimination in employment, housing, transportation, and health care. Furthermore, the nature and structure of our human service programs often contribute to the maintenance of commonly held prejudices. Continuing efforts to physically isolate individuals with disabilities from other members of the community prevents the development of mutually supportive relationships. Similarly, an over-reliance on "technologies" that can only be properly provided by specially trained professionals has made individuals with disabilities seem unapproachable to many community members. The intent of the Americans with Disabilities Act (ADA) is to eliminate all forms of discrimination towards individuals with disabilities in all public and private entities. Given the current size and unresponsiveness of the most human service systems, increased self-advocacy on the part of consumers will be required if the law is to have its intended effect.

2. **Second, the universal acceptance of the normalization concept has led to misunderstandings, misapplication, and outright corruption of the principle.**

When nearly all human service programs, even those of poor quality and design, subscribe to the philosophical principle of normalization, the usefulness of the concept as a

guiding principle is substantially diminished. A few examples of the types of questionable or outrageous practices implemented under the pretext of normalization are listed below.

- People have been told when to get up and when to go to sleep, what to eat, what to wear, the type of job they would like to have, and the types of recreational pursuits they should enjoy.

- When an individual becomes separated from his or her job as a result of being denied the basic supports he or she needed to maintain employment, this is rationalized as being tolerable - it's "normal" to lose your job.

- Children have been transported in a yellow school bus from their institutional wards across the institution grounds to a free-standing school building a quarter of a mile a way, because it is "normal" for children to ride the school bus.

- The death of an individual due to lack of supervision and concern has been rationalized as the "dignity of risk."

- A woman was denied her request for a different and shorter haircut, because it is "normal" for women to have longer hair.

- Hundreds of thousands of individuals have been "dumped" into nursing facilities across the nation in the belief that a nursing facility was a more normal place for an adult with disabilities to live than an institution.

The combined effect of these offensive misinterpretations of the normalization principle is to reduce the strength and clarity of the concept. Recent policies and regulations have concentrated less on concepts such as normal or culturally valued, while focusing significant attention on issues such as consumer-directed, consumer-responsive, and individual autonomy.

3. **Individuals with disabilities, their families, and friends have come to understand that the activity of the past two decades has created a huge, paternalistic human services bureaucracy.**

Wolfensberger (1991), looking back over the past two decades, describes the creation of a human service industry that is so large it can only fulfill its mission if a large number of individuals are viewed as dependent and "in need of" human services. The bureaucracy changes the basic needs of individuals with disabilities (e.g. housing, employment, friendship) into programs, interventions, and therapies that can only be properly supplied by members of the bureaucracy. In other words, in many cases normalization, for all the positive effects and program improvements it has generated, is too frequently reduced to one individual, usually a professional or service provider (often a person without a disability), deciding what is "normal" or "valuable" for another individual (the person with a disability). Recently, consumers have attempted to establish control over the design and delivery of the supports and services necessary for them to achieve their specific goals.

Defining Consumer Empowerment

Many different terms have been used to describe the concept of consumer empowerment. Self-determination, self-direction, consumer decision making, choice, autonomy, and self-advocacy have all been used to describe individuals exerting power over their own lives. These terms all have much in common. They all emphasize individuals making choices that direct their daily lives, exerting control over the decisions that affect their lifestyle, and asserting their rights and pursuing opportunities. In the following section, self-

determination, control, and self-advocacy (key components of consumer empowerment) are defined to illustrate the many ways this concept can be applied to supported employment.

Self-Determination

Self-determination refers to an individual's ability to express preferences and desires, make decisions, and initiate actions based upon these decisions. In essence, self-determination simply refers to **choice**. It emphasizes setting goals for oneself and then actively engaging in activities designed to achieve these goals. Supported employment programs that value self-determination would routinely ask the following questions among individuals they serve.

SUPPORTED EMPLOYMENT & SELF-DETERMINATION

- **Does the individual wish to work?**
- **What type of career or job does the individual wish to pursue?**
- **Does the supported employment consumer wish to retain his or her present position, or resign from employment because: a) the individual desires a different job; or b) the individual no longer wishes to work?**

Control

The concept of control expands and extends the principles of self-determination. Control focuses on the extent to which individuals are independent and self-sufficient. Recent federal legislation has for the first time begun to recognize the importance of consumers' control over their lives. The Developmental Disabilities and Bill of Rights Act of 1987 (P.L. 100-146) defines independence as "the extent to which persons with developmental disabilities

exert **choice and control** over their own lives [emphasis added]." Control, as the concept is used here, refers to an individual's ability to **access the resources necessary to freely act on their choices and decisions**. Whereas self-determination emphasizes goal-setting and actions designed to achieve these goals, control focuses on the extent to which these decisions are made free from excessive external influence (Wehmeyer & Berkobien, 1991 in TASH Newsletter). In supported employment services, control issues are focused on the individual's ability to direct his or her own career. Supported employment service providers who practice the concepts presented here would focus on the following areas.

SUPPORTED EMPLOYMENT & CONTROL

- **Has the individual freely chosen (WITHOUT COERCION) to participate or not participate in supported employment, as demonstrated by accepting or declining a specific job, or electing to resign or retain a specific job?**
- **Does the individual decide when and how to spend the money he or she earns through employment? Does the individual retain all earnings, or is some part of the person's wages used to support a human service agency?**
- **Are the individual's earnings and benefits sufficient to meet his or her needs? Are individuals able to pay their bills? Are individuals economically empowered to live where they choose and engage in self-chosen recreational pursuits?**

Self-Advocacy

Self-advocacy refers to an individual's ability to assert and protect his or her rights. It may occur when an individual acts alone to promote their self interest or when the individual is participating in a group. Self-advocacy has at least two dimensions. The first applies to basic legal rights and benefits available under federal and state laws and regulations. For example, when applying for employment, has the individual been treated in accordance with the provisions of the ADA and all other pertinent legislation? The second dimension focuses on participation. This dimension goes beyond simple legal rights and focuses on the individual's ability to cause change within programs and systems.

Participation in supported employment offers individuals many opportunities to engage in self-advocacy. Supported employment programs that value self-advocacy should consider the following areas.

SUPPORTED EMPLOYMENT & SELF ADVOCACY

- **Does the individual have the opportunity to select the services (specific employment specialist, type of employment model, type of job) to be delivered?**
- **Does the individual feel he or she has experienced employment discrimination?**
- **Does the individual have recourse if he or she feels that the services provided by a program or professional are of poor quality or that an employment specialist is not working hard enough on his or her behalf?**
- **Can the individual influence changes in the way services are constructed and delivered? For example, has the individual had the opportunity to be involved in the design, implementation, and evaluation of his or her supported employment services?**

Implications for Supported Employment Programs

A supported employment program designed on the principle of consumer empowerment would be very different from most of the programs in existence today. In this approach, unemployment among individuals with disabilities is viewed as the direct result of the employment discrimination they experience while pursuing their career goals. Unemployment is also viewed as being caused by a lack of necessary supports (assistive technology, personal assistant services, job coaching) in local communities. The mission of such an agency might be as follows:

> It is the mission of this agency to provide the support and services necessary to enable individuals to meet their self-chosen career goals. The agency works with individuals to assist them in making choices and career decisions. The agency is committed to assisting the individual in whatever way is necessary for as long as is necessary.

The characteristics of supported employment programs based on the consumer empowerment principle are compared to those of more traditional human services approaches in the following chart. Rather than focusing on diagnostic labels, functional deficits, perceived lack of motivation on the part of the individual, or a suspected lack of enthusiasm on the part of the individual's family, a consumer empowerment approach is far more likely to focus on uninformed employers or unresponsive components of the service system as sources of employment problems.

Comparison of a "Traditional" Approach and a Consumer Empowerment Approach to Supported Employment

Issues	"Traditional" Human Services Approach	Consumer Empowerment Approach
What is the problem?	Individual's lack of job skills or "motivation"	Discrimination Lack of supports
Where is the problem?	In the individual or his or her family	In the environment (employers, service system, etc.)
What is the solution?	Evaluate, prescribe, prepare for special services	Obtain supports only as needed to facilitate career movement
Who is in charge?	Professionals in the service system	Individual with help from support providers

A supported employment program focused on consumer empowerment would also differ from traditional programs in the types of services provided to participants. In traditional programs, individuals requesting services were first diagnosed and evaluated. Then a package of special services were prescribed from the array of available services. Individuals who needed extra assistance or required services not currently available faced difficult choices -- either accept services not designed to meet their needs or not receive any assistance whatsoever.

Supported employment services have generally tried to improve upon traditional service programs by tailoring the type and amount of services provided to the unique needs of each individual. However, far too often individuals in supported employment programs are funneled into individual or group employment options based on an agency's ability to provide services as opposed to the individual needs and preferences of consumers. Similarly,

the type of job obtained for consumers may be much more a factor of the kinds of jobs that are easy to locate, as opposed to jobs that reflect the preferences and desires of a certain individual.

In contrast, a consumer empowerment approach dictates that a supported employment program focus its energies on arranging for and providing the supports identified by the consumer as necessary to facilitate employment. This approach places the consumer much more "in charge" of their careers - making the decision to work, choosing a desired job, identifying the supports and services needed to make the employment experience a success. Adopting this philosophy may result in a perceived "loss of control" on the part of human service professionals. Obviously, the emerging trend toward consumer empowerment will lead to changes in the roles and activities of many professionals. Attempting to facilitate the vocational aspirations of supported employment consumers is a significant change from making vocational decisions on behalf of other individuals. These newly developed roles will undoubtably require extensive skills and experience. The willingness of professionals to adapt to new service approaches will have a significant impact on the rate of future change.

Recommendations for Systems Change

A number of recommendations are offered which would promote consumers' self-determination, control, and self-advocacy within supported employment programs. Most of these recommendations can be implemented at the local level only; a few may require action on the part of legislatures or administering agencies. **First, individuals with disabilities should assume control of their own careers and determine the supported employment**

services they receive. Decisions regarding whether or not to participate in a supported employment program, the type of job they obtained, and the kinds of support needed should reflect the desires and preferences of the consumer. Furthermore, the individual should feel able to select his or her own employment specialist and request more or less service from the agency as needed.

Consumers may also wish to expand their involvement in the design of the supported employment program beyond their own situation. Consumer involvement should go beyond mere token representation on advisory boards to actual membership on policy-making bodies. The knowledge and experience of individuals with disabilities should be viewed as catalysts for systems change and used to design optimally effective, responsive services.

The implementation of participatory action research and other innovative strategies can greatly increase the role of consumers in quality assurance and program evaluation activities. Participatory action research (PAR) (Whyte, 1991) is a unique approach to program evaluation and research in which some of the people in the organization or group under study participate in the design of the research, collection of data, interpretation of results, and dissemination of the results to others. When applied to supported employment, participatory action research can aid in understanding consumers' satisfaction with supported employment, consumers' level of integration in the workplace, effective marketing and job development strategies, and many other issues. Imagine, for example, the additional relevance and accuracy possible in the study of the economic benefits and costs of supported employment if consumers participate in identifying the particular costs to be studied, as well as assist in the collection and interpretation of information.

Finally, federal, state, and local governments should experiment with different funding mechanisms and program regulations that place consumers in control of purchasing or selecting their supported employment services. The lack of consumer control in the supported employment process indicates that voucher systems should be given serious consideration as major funding alternatives. Voucher systems are programs in which individuals with disabilities are allocated specific amounts of funds (credits) that will enable them to select and purchase services from an array of available programs in their local community. However, voucher systems are just one type of alternative funding arrangement. Additional systems should be developed that will promote competition among local human service providers and increase the extent to which human service providers are accountable for the outcomes achieved by participants in their programs.

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Effective Consumer Advocacy

"...Consumer organizations must come forward and boldly demand that these new laws are not merely words on paper but will truly give persons with disabilities their rights as citizens of the United States of America."

by: Ed Turner

Effective Consumer Advocacy

"Effective leadership, good communication, a purpose for being and a solid funding base are essential ingredients that go into maintaining a successful consumer organization."

What is the key to a successful consumer advocacy and/or empowerment movement? What are some important facts to remember when attempting to develop a consumer advocacy organization? These questions will be addressed in this chapter as the author shares some of his personal experiences and insights. Using a case study format the author reflects upon his personal experience organizing and developing a consumer advocacy organization. Specific information will be given on the four main areas of concern when persons with disabilities attempt to get organized for advocacy purposes: (1) selecting a leader for the organization, (2) developing a system for communicating with the membership, (3) reasons for establishing a solid funding base, and (4) potential funding options.

Case Study: Handicaps Unlimited of Virginia

As federal agencies issued regulations to implement section 504 of the 1973 Rehabilitation

Act, consumer groups from Tidewater Virginia and Central Virginia areas seized the opportunity to apply for federal funds to train consumers on these historic pieces of legislation. Persons with disabilities soon realized that these training sessions presented a unique chance for individuals and groups to meet together and discuss common issues. Out of these training sessions a new consumer advocacy organization, Handicaps Unlimited of Virginia (HUVA) was born. HUVA became Virginia's first successful state-wide cross-disability coalition. The mission of the organization was to effectively deal with the mutual concerns of the membership and to prevent the loss of rights or control of necessary programs.

HUVA's first advocacy test came in the late seventies when the federal Rehabilitation Services Administration (RSA) was issuing Request For Proposals (RFP) to states interested in seeking support for establishing Independent Living Programs. In Virginia, the state Department of Rehabilitative Services (DRS) was applying for these funds without involving consumers in the process. HUVA caught wind of DRS's plans and successfully advocated for consumers to be involved in the process. This remarkable success spurred a dramatic growth in its membership, giving birth to local chapters all over Virginia and attracting some well-known organizations as affiliates.

In the early eighties, HUVA stepped into the state political arena. HUVA's first major political event was the 1981 gubernatorial campaign between Charles S. Robb and Marshall Coleman. During the campaign, HUVA secured candidate Charles Robb's support for a system of consumer-controlled Centers for Independent Living (CIL). In addition, Robb promised that, if he were elected, he would re-enter Virginia in the Federal Development

Disabilities Program. When Charles Robb became the Governor of Virginia and followed through with his campaign promises, HUVA became the perceived voice of Virginians with physical and sensory disabilities.

By the mid-eighties, HUVA was playing a major role in helping to craft and advocate for the passage of the Virginians with Disabilities Act (VDA). The intent of this legislation is to assist persons with disabilities in the protection of rights afforded to them under the law of the Commonwealth of Virginia and the United States. Signing this legislation into law, ultimately led to the creation of the Board of Rights of Virginians with Disabilities (BRVD) and the Department of Rights of Virginians with Disabilities (DRVD). These two agencies were established to provide direct assistance to persons with disabilities as they advocate for their rights.

Once this occurred, HUVA, its chapters, and its affiliates seemed to loose its purpose. Some members and chapters believed that with the newly created CIL's, BRVD, and DRVD there was no longer a need for a state-wide consumer advocacy organization. Today, HUVA is no longer with us. The loss of this organization and its independent voice will be felt by many Virginians with disabilities.

Getting Organized

Effective leadership, good communication, a purpose for being, and a solid funding base are the essential ingredients that go into maintaining a successful consumer movement. The following section will provide the reader with practical information on leadership,

communication, and funding. It is not the author's intent to provide the reader with an exhaustive list of key considerations. Rather, the purpose is to highlight each of these major areas.

Leadership

Commitment, unselfishness, and strong motivation are qualities every effective leader should posses in order to inspire the organization to achieve its purpose and goals. Good leadership involves the entire membership in the decision-making process. When this is carried out effectively, the whole organization will have an investment in all decisions. Decisions made by a select few breeds distrust and may lead to apathy among the general membership. Periodic surveys of the general membership is a helpful method of sustaining interest while enabling to assess the feelings of the organization.

LEADERSHIP CHARACTERISTICS

- **Committed to the organization's members**
- **Motivates Members**
- **Inspires members**
- **Involves membership in the decision making process**

Communication

Communication is a vital link between an organization's leaders, member organizations, and/or individual members. One cost effective method for establishing regular communication is through the development of a newsletter. A newsletter that is sent to local organizations on a frequent basis is one key way to maintain open lines of communication. Using the telephone and maintaining a list of contacts to be made routinely is another method for establishing a system for communication. Regular telephone calls made to Presidents of local chapters and/or individual members will be essential for keeping information flowing in both directions. A critical goal in the communication process is to appraise members of the organization's activities as well as local, state, and national concerns. Developing strong communication linkages will build a cohesive and close-knit consumer movement.

COMMUNICATION CHARACTERISTICS

- **Communication forms a link between the organization and the membership**
- **Communication is a two way process**
- **Communication uses a variety of methods**
- **Communication shares state level information**
- **Communication assists members in keeping up with local concerns**

Funding

Establishing a solid funding base will be critical in the overall success and longevity of an organization. Funding will guide many of the practices of an organization. For example, it will determine how frequently written communication can be distributed to the membership. An organization can be highly committed to developing strong communication linkages with its membership yet be unable to implement any of the strategies identified in the above section without adequate funding. Funding will also determine an organization's involvement on a particular advocacy issue. Simple things such as reimbursing members for travel expenses when performing important organizational business may be an impossibility if the proper funds don't exist. Establishing a solid funding source for a consumer advocacy organization will require a great deal of thought and planning.

There are several funding possibilities that an organization may want to consider (1) grant funding; (2) membership dues or; (3) innovative funding options. The type of funding an organization attempts to secure will be a major issue for the organization to agree upon. Securing grant funding is one possible funding source. Grants, though called for a short time, can limit the scope of advocacy efforts. For example, the organization may feel very committed to a specific project but may not be able to get involved if the organization is 100% funded and resources can only be used to carry out the specific purpose of the grant.

A second funding possibility is the use of membership dues to build a solid funding base. While this is a good idea, it may be unrealistic if the majority of the membership is on fixed incomes. However, if this method does not prove to be realistic for the reason

presented here, members should still be encouraged to pay their fair share. This will measure their commitment to the organization.

A third possible funding source is for the organization to develop innovative funding strategies. An example of an innovative funding idea would be for the organization to lend its name to local business. If an organization chooses this particular funding option, careful analysis should be conducted concerning the organization's philosophy and practices.

In reality, most organizations will choose to use a variety of funding options. Generally, organizations will use several funding options at the same time. Typically, the options will vary depending upon the make up of a particular community.

FUNDING CHARACTERISTICS

- **Establish long term funding options**
- **Select a funding option consistent with organizational philosophy**
- **Identify funding options that promote membership commitment**
- **Use multiple funding strategies**

Summary

The twelve year history of HUVA gave me an insight into what makes a consumer organization successful, and what contributes to its demise. A successful organization must begin with a strong purpose such as involving consumers in the Independent Living Movement, training consumers on historical pieces of legislation that have a direct influence on their lives, or teaching consumers how to advocate for their rights. The organization must provide training to new leaders who will eventually replace individuals as they move on to other endeavors. Service providers, a gubernatorial appointed board, or a state agency can never speak with the same freedom that is available to an independent organization. Political expedience will never allow this to occur. Even with recent legislation that is intended to protect the rights of persons with disabilities, there is still the need for a strong consumer movement. Independently based consumer advocacy organizations can ensure the full implementation of these laws. In fact, consumer organizations must come forward and boldly demand that these new laws are not merely words on paper but will truly give persons with disabilities their rights as citizens of the United States of America.

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